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A STUDY TO DETERMINE COMMAND GUIDANCE REQUIRED BY REGISTERED NURSES IN THE MANAGEMENT OF TERMINALLY ILL PATIENTS DURING PRE-DEATH WHEN NON-RESUSCITATIVE MEASURES ARE IMPLIED

A Graduate Research Project
Submitted to the Facility of
Baylor University
in Partial Fulfillment of the
Requirements for the Degree
of
Master of Health Administration

By Sandra V. Ross Major, ANC

May 1984

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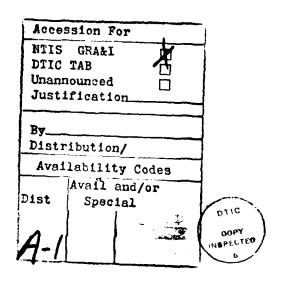
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I. INTRODUCTION

Ethical/legal issues in health care are assuming increasing significance due to the emotional issues, media coverage, and high health care cost. This has resulted in growing public awareness over patients' rights, malpractice and death and dying issues. Concern over the decision of when not to attempt resuscitation on a patient and how to implement that decision is certainly one of the most dramatic, complicated and yet common of these issues.

Before the development of effective cardiopulmonary resuscitation techniques and other modern life support systems, the issue of whether to provide or forego life prolonging treatment was of little concern. Physiologic life can now be extended through medical technology even after all meaningful life is extinct. Despite modern technology, we must keep in mind that death is a natural and inevitable event that may be the preferred course for some individuals. From the physician's point of view, death is the ultimate enemy; he is taught to prolong life whenever possible. He is also asked to relieve suffering and to do no harm. It has become increasingly difficult to determine when the tests and treatments directed at saving a patient's life are, in fact, no longer in the best interest of the patient.

Many factors are involved in making the medical determination that resuscitation is not to be a part of the

patient's medical treatment. Included in these factors are personal and professional experiences of the health care provider, communication with the patient and his family, legal issues to include fear of malpractice, knowledge about the patient's disease and the process of dyino. Standards and quidelines for cardiopulmonary resuscitation (CPR) and Emergency Cardiac Care (ECC), published by the American Medical Association, specify that CPR is intended to prevent sudden unexpected death and is not indicated in cases such as terminal irreversible illness where death is not unexpected. It is even possible that in some situations resuscitation represents a violation of a person's right to die with dignity. 4,5,6, However, CFR is ordinary medical care and only the patient has the right to refuse this care if he is able to do so. Failure to obtain the patient's permission might be construed as passive euthanasia and the physician held liable.7

The Dinnerstein decision allowed that "no code" - the decision not to attempt resuscitation, could be an appropriate course of medical treatment for a comatose patient if the attending physician determined that the patient was irreversibly, terminally ill. B, Shirley Dinnerstein was a comatose, terminally ill patient. A Massachusetts probate court ruled that a no code could be appropriate, in this case after the physician made the decision and the family concurred that resuscitation attempts were not appropriate. Most cases remain unresolved as

to whether family, patient, physician or court will individually or jointly be responsible for the decision to withhold CPR. 11,12

The responsibility for the dying process has been usurped by health care professionals; the terminally ill patient is no longer assured that his death belongs to him as a meaningful summation of his life. 13,14 Resuscitation is a traumatic event, a violent intrusion into what might have been the peaceful final state of life. 15 Long-term survival rates after CPR for a terminally ill patient are very low, and frequently CPR only prolongs the dying of an already comatose patient. 15,17 suitability of patients for CPR treatment should be determined prior to the need for such action if both the patient and the hospital staff are to be adequately protected and the best medical/nursing care given. 18 If a "Do Not Resuscitate" (DNR) decision is a possibility for a terminally ill patient who is no longer responding to medical treatment or who desires no further medical intervention, the physician must analyze the situation, initiate the communication needed for that decision to be acceptable for all involved, and implement the decision in a manner that insures the patient receives the type of care desired when death approaches. This must be done while maintaining the hospital staff within legal parameters of good medical practice. The physician must also insure that a patient who should be resuscitated or who desires to be resuscitated, is, in fact, given that care when needed. Lack of good communication under

either situation causes pain, bitterness, distrust and risk of litigation. 19

The decision that CPR is not a suitable treatment is a critical turning point in the care of the terminally ill patient. Since this determination may be made weeks prior to the death of a patient, the focus and subsequent quality of care now hinges on what is perceived by "comfort" oriented care as opposed to "curative" oriented care. Dying carries with it an aura of failure. The attitudes and behavior patterns of the staff greatly determine the social context in which dying occurs. The work of Elizabeth Kubler-Ross on death and dying, and the subsequent hospice movement have raised the social awareness concerning care of the dying patient. But within the hospital setting there is little agreement about the criteria for making a "no code" decision, or what palliative care encompasses. 21,22

Whether DNR decisions should be made, how they are made, and how they are implemented are the source of much legal, medical and ethical debate. The literature supports a hospital policy and documentation of the decision. 23,24,25 When a hospital does not have a policy, the approach to making a DNR decision lacks uniformity, which creates an unstable environment resulting in confusion for the hospital staff at the time of a cardiopulmonary arrest. 26,27

The Army Medical Department (AMEDD) has been informed by a decision passed down from the Judge Advocate General (JAG) to the

Surgeon General of the Army that neither living wills, natural death acts, nor physician directives, all of which refer to cardiopulmonary resuscitation, could be included in the patient's chart as guidance to withhold treatment. 28 At the 1982 Army Chief of Professional Services (CPS) Conference, these top executive physicians were informed by a JAG representative from Health Services Command (HSC) that orders not to resuscitate, such as "no code", were illegal and should not be written. 29

Another agency that has been reviewing care of the terminally ill is the Joint Commission on Accreditation of Hospitals (JCAH). The commission is in the process of proposing standards for hospice care. Hospice care is palliative, supportive care for the terminally ill and their families with an emphasis on psychological support and control of pain. 30 A letter from Barbara McCann, Hospice Project Director, stated that patients entering a hospice program should understand that the care is palliative and that extreme life saving measures will not be taken. She went on to say that this assumption cannot be made in any other department or for other terminal patients.³¹ Considering the limited availability of hospice programs and the lack of provision under Army Regulation 40-3 for a hospice program in the AMEDD, there appears to be a large gulf between Hospice care, which should be optimal care for the terminally ill, and the care given to all non-hospice, terminally ill patients approaching death.

The nurse practice acts of most states indicate the nurse must follow the doctor's order unless she determines the order is inappropriate and could harm the patient. When the physician refuses to write a DNR order but gives it verbally or indicates the patient is irreversibly, terminally ill, the true decision of whether to initiate CPR and how vigorously often falls to nursing judgment regardless of whether this is appropriate, legal or even acknowledged. 32,33,34,35

There is much more to care of the terminally ill than making a decision about resuscitation, but much of the care direction, especially supportive communication, is determined by that decision. If health care professionals cannot document a DNR decision by writing an order, and if there is no hospital policy on DNR decisions, the questions arise; do nurses understand their role in the care of dying patients; or do they have clear guidance from the hospital as to their role when "no code" is implied, and if not, what guidance do nurses need?

The conditions which prompted this study were highlighted during the Fall of 1982 when confusion was expressed by the nursing and medical staff at Moncrief Army Community Hospital (MACH) over the lack of an explicit hospital policy detailing the procedure for documenting a DNR decision. The Chief of Professional Services attempted to establish a policy but had to abandon this approach as directed from Health Services Command. All the ethical, legal, and medical aspects of the DNR decision

surfaced in discussion. It was apparent that there were many varying viewpoints as well as varying practices concerning care of terminally ill patients.

This study is an attempt to clarify what registered nurses perceive as their role when caring for a terminally ill patient for whom "no resuscitation" is implied in their chart. Results of the study should assist the executive staff of this hospital in determining what guidance they need to provide to insure quality care and adequate risk management.

II. STATEMENT OF THE PROBLEM

The problem was to determine: the local command guidance required by nurses in situations where there is an implicit indication in a terminally ill patient's medical record requesting non-resuscitative procedures either by patients or family and/or primary physician.

III. OBJECTIVES, CRITERIA, ASSUMPTIONS, AND LIMITATIONS Objectives

The objectives of this research were to:

- 1. Identify the current applicable laws, regulations and policies regarding the decision not to resuscitate a terminally ill catient.
- 2. Determine the approximate annual patient population at MACH to which this research is applicable.

- 3. Make explicit the current guidance from this Hospital Commander and the Chief Nurse.
- 4. Identify those nurses who provide care to terminally ill patients.
- 5. Determine a consensus of concerns and issues from the nurses applicable to this problem which require guidance.
- 6. Determine what guidance can be given under existing legal constraints.
- 7. Determine how the needed guidance can best be given at Moncrief Army Community Hospital.

Criteria

The established guidance are consistent with:

- 1. Guidance set forth by the Surgeon General and HSC JAG.
- 2 Joint Commission standards and Army regulations pertinent to documentation in a patient's chart.
- 3. Federal laws, South Carolina State Laws, and legal precedents as they are pertinent.
- 4. Position statement of the American Medical Association (AMA) and other professional associations, to include the County Medical Society and the South Carolina State Nurses Associations.
- 5. Response rate to the survey document was at least 70% to justify a conclusion on consensus.

Assumptions

Assumptions of this research were:

- 1. That individuals surveyed responded truthfully, accurately and independently.
- 2. That the AMEDD will continue to operate under the Surgeon General's guidance that neither the Surgeon General's Office nor the individual hospital commands will issue a written "no code" policy.

Limitations

Limitations of this research are:

- 1. Only nurses at MACH were surveyed.
- 2. Only Federal and South Carolina State Laws were applied.

IV. RESEARCH METHODOLOGY

Data Collection

- 1. Current directives within the AMEDD were obtained from HSC JAG.
- 2. South Carolina and Federal laws were reviewed to determine valid legal constraints which apply.
- 3. JCAH was contacted to clarify their position on any aspect pertinent to this research.
- 4. The 24-hour Nurses Report was used to identify patients who died from a terminal illness during FY 82 and FY 83, who had been hospitalized at least 48 hours. The charts of these patients were reviewed to verify the proper classification of these patients and to determine which staffs of nurses should be included in this research.

- 5. An extensive literature review was conducted to assist in identifying common nursing concerns and issues regarding the limitation of resuscitation with the terminally ill. This information was used in designing the questionnaire.
- 6. A questionnaire was designed, distributed, collected, and analyzed regarding command guidance needed and type of care to be provided to the terminally ill patient and their family or significant other when non-resuscitative procedures are implied. The questionnaire was distributed to the nurses identified in item four. Imply for this research was defined as written indication in the doctor's progress notes that the patient and/or family no longer wants aggressive curative measures to be taken to sustain the patient's life. If the physician did not state that care should be aggressive, then it was assumed that the physician agreed with the decision. Statements such as "the patient's condition was discussed with the family and they wish no heroics", or "the patient desires comfort measures only", were considered as implying non-resuscitative procedures would be the course of treatment.

Recording the Data

- 1. All current directives, regulations, or standards were referenced if applicable.
- 2. Results of the survey questionnaire were analyzed and recorded.
- 3. Laws, legal precedents and specific cases were incorporated as appropriate.

4. Position statements from recognized professional organizations were referenced where applicable.

Data Evaluation

The demographic questions were used to develop a demographic profile of the respondents using descriptive statistics.

The twenty-five questions and all subcomponents of questions were designed using a Likert type attitudinal scale. This survey used a range of seven possible responses ranging from one, strongly disagree to seven, strongly agree. The response of four represented a neutral attitude concerning the questions being posed. The measurement of all survey questions was accomplished by computing the mean and standard deviation (SD) of each question.

Although the sequencing of the category of question followed a logical order, the questions which were grouped together for analysis and comparison did not necessarily appear together on the survey questionnaire. Tables seven through fourteen group the related questions and responses together to facilitate comparative and subjective analysis of the survey results. Questions were occasionally used in more than one Table. Survey questions 1, 2, 19, 20 and 21 were grouped in Table 7 under Nurses Preparedness. Table 8, Direction of Care, grouped questions 3, 6, 13, 14, 22 and 23. Table 9 grouped questions concerning communications, questions 8, 9, 10, 11, 24, and 25. Table 10 dealt with the problem of CPR without a written order,

question 18. Related questions 13, 22 and 23 were also used in this Table. Questions 3 and 4 were grouped in Table 11 under Quality of Life. Table 12, Ward Rules and Privileges, used questions 5, 6 and 7. Table 13, Comfort Measures used questions 14 and 15. The last Table, Table 14, group questions 12, 16 and 17 under the category of Innovative Approaches.

A mean of five or greater was considered to be significant and indicative of those items that should be addressed in the command guidance for nurses when caring for terminally ill patients. Specifically addressing those patient care items with a mean of five or more is expected to help clarify for the nurses whether or not the command is supportive of the care the nurses are rendering, or wish to render, to the terminally ill patient regardless of the fact that there is not a "no code" policy nor is "no code" a written order on the patient's chart. Questions not relating directly to patient care are expected to clarify to the command the atmosphere currently surrounding nursing care of terminally ill patients. Analysis of those questions indicates areas which require specific command direction of action. Example -- if education in the area of terminal nursing care is a significant problem then the command may wish to establish an education program. It was felt by this researcher that a mean of five would indicate that the subject of the survey question was of concern to the registered nurses or already part of the care being provided and therefore warranted consideration in the

development of command guidance. It was also felt that some of the most controversial subject areas would have a mean less than six, thus, to allow for comprehensive and meaningful information upon which to develop command guidance, the mean of five was selected.

Survey question replies having a standard deviation of greater than 1.5 were compared with other related questions to determine if there were a diversity in the answers indicating a problem area which requires command guidance.

The standard deviation measurement of 1.5 was selected by this researcher. This again was a subjective determination selected after considering the range of the survey tool, the significant mean being used, and the intent of the survey tool and this research. The comparison of survey question result among related questions assisted in insuring that the analysis was a realistic reflection of the concerns and beliefs of the registered nurses and not a flaw in the survey instrument.

The questionnaire used was designed by the writer, underwent expert review for face validity as well as a pilot study. The expert reviewer was a Ph.D. nurse researcher. The pilot study utilized a nurse educator, an Infection Control nurse with a background in Medical/Surgical nursing, an Ambulatory Care Clinic Head Nurse who is also an oncology nurse specialist, and a Medical Nursing Supervisor. Minor changes identified by the pilot study were incorporated.

The final results of the guidance needed were compared with legal and professional restrictions to determine what guidance can be given to address the specific concerns and issues identified, within the constraints. The general form of the recommended guidance was included in the recommendations.

FOOTNOTES

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²⁹Molnar, Albert C, COL Chief, Professional Services, Moncrief Army Hospital, Ft. Jackson, South Carolina, (November 16, 1982).

30 Henry Rolka, "Quality Assurance for Terminally III," Hospital and Health Services Administration, (March-April 1983), 72.

31 Letter dated January 10, 1983 from Barbara McCann, Hospice Program Director, Joint Commission on Accreditation of Hospitals.

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33 Diane Adler. "No Code - The Unwritten Order," Heart and Lung, (March-April 1977), 213.

34 Mary Catherine Halloran, "Rational Ethical Judgments Utilizing a Decision-Making Tool," Heart and Lung, (November - December 1982), 570.

 $^{35}\mathrm{Judith}$ Brown, "No Written Order for No Code," Nursing 81. (December 1981), 94.

³⁶Wayne Daniel, <u>Biostatistics: A Foundation for Analysis in the Health Sciences</u> (New York: John Wiley and Sons, 1978), p. 359.

PRESENTATION AND DISCUSSION OF DATA

Current Laws, Regulations and Policies

South Carolina has no legal precedence established concerning care of terminally ill patients or specifically the legality of comfort-oriented, non-resuscitative care as opposed to curative, resuscitative care. Non-resuscitation of hopelessly, terminally ill patients appear to be an acceptable standard of practice even though not formally or legally acknowledged.

Health Services Command (HSC), at the guidance of the Surgeon General has directed its hospital commanders not to establish "no code" policies or to have physicians write "no code" orders, but instead to review the circumstances of each case and make individual, independent decisions about the appropriateness of resuscitative attempts for that patient. MACH command has passed on the Surgeon General's and HSC's guidance to the physicians but has not issued specific directions to the physicians or nurses concerning how to determine the appropriateness of care or the implementation of any noncurative, non-resuscitative care, (Appendix C). A discussion with Colonel Gibbs III, Chaplain, HSC, and Colonel Molnar, Moncrief's Deputy Commander of Clinical Services, revealed that part of the vagueness surrounding care of terminally ill patients stems not only from a lack of "no code" policy but also from this Army hospital's mission which is focused on health care for the

active duty soldier. At this time, Army hospitals do not acknowledge that they provide terminal care on a routine basis. Army Regulation 40-3 does not provide for hospice care or home health care which have been associated with terminal care. There has been no consensus on how to provide better in-hospital care of terminally ill patients without committing excessive resources to this small group of patients.

The Survey Instrument

The registered nurse questionnaire on care of the terminally ill patient was designed, pretested, then distributed to all the registered nurses on the medical ward, the surgical ward and the Pediatric/Gynecology ward. A review of the 24-hour nursing reports (DA 3889) for fiscal year 1982 and 1983 revealed an average of thirty-five patients per year who had a diagnosis indicative of a terminal illness and who died at MACH after at least a 48 hour hospitalization. A review of those charts insured proper classification of those patients in terms of this study. In addition to the three wards indicated above, occasionally an apparent terminally ill patient died in one of the intensive care units. The intensive care areas and those patients were eliminated from this study as their focus of care continued to be curative in nature.

F total of twenty registered nurses were surveyed. Nineteen questionnaires were completed and returned for a final response rate of 95 percent. The survey instrument consisted of two

segments. The first segment contained six demographic data questions. Part two contained twenty-five questions about care of terminally ill patients. Three questions of the twenty-five had multiple parts. Those questions dealt with concepts of comfort measures, privileges and quality of life items. A Likert type attitudinal scale was used with seven choices ranging from strongly disagrees to strongly agrees. A mean result to each question was obtained by multiplying the number of responses in each category times the number given to that response, adding those numbers together and dividing by the total number of responses to that question. A mean score of five or more was considered significant to the problem statement. Additional analysis has also been made regarding the pattern of responses to related questions, individual comments made, and standard deviations of 1.5 or greater.

Demographic Characteristics

The demographic data revealed the following profile. The average nurse responding was a female, military nurse between the age of 27 and 34 years who practiced on a medical or surgical ward. This nurse held a bachelors degree in nursing and had cared for six or more terminally ill patients during the end stages of their disease.

The specific demographic breakdown was as follows:

TABLE 1

Age Distribution of Respondents

AGE GROUP	NUMBER	PERCENT
26 or younger	2	10.5
27 - 34	6	32.6
35 - 42	6	32.6
43 - 50	1	5.3
Over 50	4	21.1

TABLE 2

Current Areas of Practice

AREA	NUMBER	PERCENT
Medical	8	42.1
Surgical	7	36.8
Pediatrics	4	21.1

TABLE 3

Sex Profile of Respondents

SEX	NUMBER	PERCENT	
Male	1	5.3	
Female	18	94.7	

TABLE 4

Employment Status

STATUS	NUMBER	PERCENT
Military	12	53.2
Civilian	7	36.8

TABLE 5

End Stages Terminally Ill Patients Cared for by Respondent

NUMBER OF PATIENTS	NUMBER	PERCENT	
1 -5	3	15.8	
6 or more	16	84.2	

TABLE 6

Nursing Education of Respondent

LEVEL	NUMBER	PERCENT
Diploma	7	36.8
BSN	10	52.6
Other	2	10.5

Results and Analysis of the Preparation of Nurses for Caring for Terminally Ill Patients

Five questions (1, 2, 19, 20 and 21) dealt with the nurses' preparedness for caring for terminally ill patients and her understanding of command guidance. Table 7 lists these questions and displays the statistical analysis. Generally the nurses slightly agreed that they faced a great amount of uncertainty of how to work in particular settings with terminally ill patients. they slightly disagreed that they lacked education in managing these patients and slightly agreed that they were adequately prepared to care for the terminally ill and their significant others. When asked about understanding what was expected of them and if they felt explicit guidance was needed, they slightly agreed they understood their responsibility but moderately agreed that explicit quidance was needed. Individual comments indicated that guidance was needed for legal protection if for no other reason. One respondent stated that she wanted guidelines for legal protection only; her moral decision had already been made. Another respondent answered that, "Ever since the HSC policy of no "no code" order, "I'm not at all sure of what's expected of me when an obviously terminal patient arrests."

It appears, therefore, that although educational preparedness is minimally adequate; a significant amount of confusion exists concerning command expectation, guidance, and legal responsibility. Also noteworthy is the fact that the

standard deviation for all five of these questions was over one with three being over 1.5 indicating considerable variation in the answers to these questions.

TABLE 7

Nurses Preparedness

STANDARD DEVIATION (50)	1,39	1.72	1.7	2,15	1.3
MEAN	5.4	4.3	5.2	۲۵	6.3
QUESTION	 Nurses face a great amount of uncertainty on how to work in particular settings with terminal patients. 	2. Most nurses lack education in the management of terminally ill patients.	19. You are adequately prepared to provide care to terminally ill patients and their significant others.	20. You clearly understand what is expected of you in the care of terminally ill patients.	21. You would like explicit quidelines regarding nursing care of terminally ill patients and their families when non-resuscitative measures are implied in the medical record.

Results and Analysis of Direction and Focus of Nursing Care with Terminally Ill Patients

Six questions (3, 6, 13, 14, 22 and 23) dealt with general concepts about the direction and focus of care and nursing judgment when caring for terminally ill patients. These questions relate to quality of life, hospital privileges and comfort measures for the terminally ill. Table 8 lists these questions and displays the statistical analysis.

The nursing goal of improving the patient's quality of life ranked a high 6.7 mean. Attitudes about independent nursing judgment and the nurse's need to be able to relax rules and employ comfort measures also ranked high at 6.2 and 6.4 although the S.D. for independent judgment was 1.85. The S.D. for questions concerning the need to verify a "no code" status and if that affected nursing care were also over 1.5; however, 68% strongly agreed the focus of nursing care changed when the "no code" decision was made, and 63% of the respondents felt strongly that it was essential to verify a "code/no code" status to properly plan nursing care. It can be inferred from these responses that this group of nurses felt that the "code" or "no code" decision significantly affects the appropriateness of the nursing care given. It also appears that the nurses feel that independent nursing judgment directly contributes to the quality of care provided terminally ill patients.

ARIFA

Direction of Care

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• •	tuation. sing care involves independent nursing nt based on the patient's diagnosis and d outcome.	tuation. ssing care involves independent nursing nt based on the patient's diagnosis and ed outcome. nurse should be authorized to initiate loy any comfort measures she/he determines eded.	the situation. 13. Nursing care involves independent nursing judgment based on the patient's diagnosis and expected outcome. 14. The nurse should be authorized to initiate or employ any comfort measures she/he determines are needed. 22. The focus and nursing care approach for a terminally ill patient changes from curative to supportive and comfort once a non-resuscitative plan is implied.

Results and Analysis of Communication Between the Nurse and the Physician, Patient and Significant Others

Six questions (6, 9, 10, 11, 24 and 25) dealt with various aspects of communication. These questions and their statistical analysis are listed in Table 9.

Overall, the importance of good communication rated a high The nurses felt it important to keep the physician informed of the patient's and family needs as well as the nursing care being planned. From a quality of care and risk management viewpoint, they rated communication high as a positive contributing factor, especially where perception of care was concerned. Additional explanations as needed by the patient was also perceived by the nurses to be part of their role, although there was less group agreement to this question. The responses to the remaining two questions, eight and ten, resulted in means below the significant level. However, these two questions had very large standard deviations, 1.92 and 2.8 respectively, indicating a large division in the responses to these questions. Question eight dealt with the nurse sharing the patient's chart with him or family as they expressed a need to know what was happening. Although 63% of the nurses agreed with this statement to varying degrees, there was enough disagreement to lower the mean to just below the significant level for this research. Several nurses stated they were willing to share the information but not necessarily share the chart. Question ten resulted in the largest division of responses than any other question. This question dealt with the nurse's and family's or significant other's communication about the type of care to be given when death appeared eminent and "no code" had not been made explicit to all concerned. Forty-two percent of the respondents strongly agreed that the nurse should approach the family and the same percent strongly disagreed, stating that this was the physician's responsibility.

TABLE 9

Communication

Results and Analysis Concerning the Question of CPR When "No Code" was Implied But Not Written

Only question 18 dealt directly with the decision of whether or not to initiate CPR at the time of cardiac or respiratory arrest of a terminally ill patient if a specific order has not been written, which applies to all terminally ill patients at Moncrief at present. Table 10 shows this question and two related questions and their statistical analysis.

The mean results of these questions showed that on the average the nurses slightly agreed that CPR should not normally be initiated. the large standard deviation of 2.34 indicates considerable disagreement in the responses to this question. A total of 53% strongly agreed that CPR should not normally be initiated if "no code" was implied but not a written order; 21% strongly or moderately disagreed; another 16% were neutral. It is obvious that at this time whether or not CPR is initiated when a terminally ill patient arrests is not dependent upon hospital guidance but upon individual nurses attitudes which may or may not promote the most appropriate care. Referring once again to questions 22 and 23 concerning the need to have a "code" or "no code" decision point, the responses indicated a need for that decision to properly direct the nursing care.

1.85

1.97

1.89

TABLE 10

CPR Without a Written Order

80

2.34

RELATED QUESTIONS

6.2	5.9	۲, ۲
13. Nursing care involves independent nursing judgment based on the patient's diagnosis and expected outcome.	22. The focus and nursing care approach for a terminally ill patient changes from curative to supportive and comfort once a non-resuscitative plan is implied.	23. It is essential to verify the code/no code status of a patient if appropriate nursing care is to be given.

		5.7
the code/no	appropriate	
23. It is essential to verify	code status of a patient if a	nursing care is to be given.

Result and Analysis of Specific Innovative Approaches to Care for the Terminally III

The remaining survey questions addressed varying aspects of patient care approaches that might be employed by nurses caring for terminally ill patients. These questions and their statistical analysis are shown in the following tables.

Table 11 lists quality of life questions. Quality of life for patients and their families as a goal of nursing care was given a strong 6.7 mean. In an attempt to determine what nurses might include in nursing care as quality of life items, question 4 listed eleven items, all of which the respondents replied to with a mean well over five. Two questions had a S.D. greater than 1.5. These questions concerned decreasing diagnostic intervention and increasing the patients functional activity. It may be that some nurses do not view these as nurses' responsibilities or there may have been some uncertainty as to the interpretation of the question and the nursing role.

Individual comments referring to quality of life reemphasized that these items must be "as the patient desires." Another respondent added the item, "to facilitate communication between staff and the patient's family."

Quality of Life

TABLE 11

		(
QUESTION	1 H	31	
3. The goal of nursing care for the terminally iil is to improve the quality of life for the patient and his family.	6.7	.73	
4. Improved Quality of Life might include the following items. Indicate you agreement or disagreement with each item in this category.			
associated with the disease.	6*9	.22	
b. In decrease depression anxiety, and anger.	6.4	1.23	
c. In increase satisfaction of care.	6.7	.73	
d. To improve the physical environment.	6.3	85	
e. To decrease diagnostic interventions (Lab and Radiographic test).	5.7	1.58	
f. To increase opportunity to affect the course of treatment.	9	1.18	
g. To increase choice of location of care and death.	6.5	66.	
h. To increase patient's functional activity.	ர .	1.54	
 To decrease the family's ill effects during bereavement. (Help the family understand and cope with the events surrounding terminal illness). 	6 •8	.41	
j. To promote open communication between signi- ficant others and patient about death.	6.3	1.21	
k. To assist patient in making final preparation as desired.	p*9	86.	

Ward rules and privilege questions are listed on Table 12. Although the nurses responded strongly that hospital rules should be relaxed for the terminally ill patient and the charge nurse should use her own discretion in relaxing these rules, when given a list of thirteen possible privileges that are commonly referred to in the literature when discussing terminal care and hospice care, the responses showed considerable reserve in several areas. Visits by small household pets and smoking ranked below the significant level. Wearing of own clothes and allowing direct admission to the ward were significant but with a S.D. greater than 1.5. Adult visitors at any time, visits by children and alcoholic drinks in moderation were all within the significant range.

Individual comments concerning rules and privileges added some additional privileges that several nurses felt were important:

- Direct access to telephone or own telephone line.
- Comfortable in-room sleeping facilities for family members who desire to stay.
- Availability of meals for family members in the patient's room if desired so the family could enjoy a meal with the patient.

TABLE 12

Ward Rules and Privileges

ME AN SD	6.8 .53	6.6		5.6 1.27	5.9 1.45	4.4 1.77	4.9 1.51	5.6 1.34	6.9	6.8 .63	89. 9.8	6.3 1.56	6.9 1.23
QUESTION	5. Hospital and ward rules should be relaxed to accommodate the physical, psychological and social needs of the terminal patient as long as care to other patients is not impaired.	6. The charge nurse should have the right to relax ward rules as she/he deems appropriate for the situation.	7. The following is a list of items that might be considered as privileges for the terminally ill. Please indicate your degree of agreement or disagreement with each item.	a. Adult visitors at any time.	b. Visits by children.	c. Visits by small household pets.	d. Smoking.	e. Alcoholic drinks in moderation.	f. Television, radio or tape player left on when desired.	g.Special personal items brought to hospital (Ex: pillow, tape recorder, chair).	h. Privacy as desires.	i. Wearing own clothes.	j. Allowing patient to go outside the hospital as much as possible with family or friends.

TABLE 12

Ward Rules and Privileges

(Continued)

SO	1.57	06•	.83
MEAN	5.6	6.6	6.6
QUESTION	k. Direct admission to the ward when the patient or family feels the need for hospitalization (bypass the Emergency Room whenever feasible).	l. Any type of food from outside the hospital.	m. Allow patient to participate in decisions about his care.

Comfort measures received a very positive response from the nurses who moderately and strongly agreed that the nurse should employ any comfort measure she determined necessary. Table 13 lists the questions and statistical analysis for comfort measures. On this list of possible comfort measures all were significant with a mean of 6 or greater except for the insertion or removal of a nasal gastric tube for comfort. These two had means between four and five and S.D. greater than 1.5. Individual comments gave some possible additions to the list of comfort items:

- Availability of special dietary items requested such as milkshakes or steak.
- Self-hypnosis and relaxation technique instruction
- Heating pags or cold packs
- Emotional spiritual care, scripture readings, tapes, films or prayers, if patient desires
- Devices to decrease venipunctures such as longterm, surgically implanted atrial catheters
- Continuous morphine drip for pain control and use of marijuana for nausea related to chemotherapy.

The last two items could be suggested by nurses but would require a physician's order or intervention. The use of marijuana is not legally approved at this hospital.

TABLE 13

..........

Comfort Measures

QUESTION	MEAN	SD
14. The nurse should be authorized to initiate or employ any comfort measures she/he determines are needed.	6.4	.87
15. The term "comfort measures" might include the following items to be initiated by the nurse. Please indicate your agreement or disagreement with each item.		
a. Positioning.	6.9	.22
b. Skin care.	7	0
c. Oral hygiene and lip care.	7	0
d. Suctioning.	9.9	.68
e. Oral air way.	6.4	.77
f. Skin care devices or equipment (Ex: Air mattress, sheepskin).	7	0
g. Oral fluids or nutrition as tolerated.	6.9	.22
g. Oxygen on (if patient desires).	9.9	.75
i. Oxygen devices taken off (Ex: Nasal canula or mask if uncomfortable).	9	76.
j. Nasal gastric tube inserted.	4.2	1.85
k. Nasal gastric tube removed (if patient desires).	4.7	2.23
l.Room environment adjusted (Ex: temperature, lighting, noise level).	6.8	. 45

TABLE 13

Comfort Measures

(Continued)

	QUESTION	MEAN	20
Ē	Lubricating eye drops.	6.2	1.86
Ċ	Bathing, hair shampooing, shaving.	6.9	.22
o. sleep.	o. Flexible schedule to allow patient to	6•9	.31
ō.	Ador control in room.	7	0
ō	Therapeutic-touch.	6.8	.36
Ħ	Nail care, make-up as needed or desired.	6.9	.31
'n	Pain medication as ordered if needed.	6.7	1.34

The last three questions to be analyzed independently address additional innovative approaches that might be used when caring for the terminally ill. These questions and their statistical analysis are listed in Table 14. All three questions had significant means although the use of a nurse resource person had an S.D. of 1.73. The indication by the response to these questions is that the nurses are interested in utilizing all possible resources to improve the quality of care to terminally ill patients.

Two additional comments that were written in the survey responses. These comments reflect a problem the nurses have in the care of terminally ill patients, the problem of insufficient nurse resources to accomplish all the care the nurses would like to provide. One respondent stated, "I do not have the time to provide adequate care to patients and significant others much of the time." Another nurse commented that she feels a separate unit is needed for the terminally ill, that providing this care on a busy surgical ward placed too much strain on the staff, patient and families. She added that families need to interact with other families with similar circumstances.

TABLE 14

Innovative Approaches

읽	1.70	. 71	.67
MEAN	5.4	6.7	6.8
QUESTION	12. One nurse resource person should be assigned to each patient and his family for them to contact at <u>anytime</u> they feel they need.	16. Routine multi-disciplinary (Dietitian, Social Service, Chaplain, Physical Therapist, etc.) hospital rounds should be conducted to assist in developing the patient's care plan.	17. Supportive care for the patient includes supportive care for the family, regardless of their military eligibility.

CONCLUSIONS AND RECOMMENDATIONS

Conclusion

Analysis of the questionnaire reveals three areas in which the nurses are seeking clarification of formal guidance, as well as many patient care items they believe should be accepted as routine nursing practice in the care of terminally ill patients. The three areas requiring clarification by the hospital command are command expectations, formal command guidance and the nurse's legal responsibility or position while providing terminal care. These three areas are not unique and independent from each other but rather a blend of issues each affecting the other. Since this study is focused on determining the command guidance required, it is expected that command expectations and legal guidance will be incorporated into any command guidance given.

The analysis of the questions indicated the following issues need to be addressed in any command guidance provided: (1) When "no code" is implied in the progress notes but no order is written, what is expected of the nursing staff when the patient arrests. (2) Are the nurses in good legal standing if they follow implied directions not to initiate CPR? (3) What constitutes communication of a "no code" decision from the physician to the nurse. If a direct "no code" order is not to be written, should the progress notes contain a clear indication that the patient is at the end stage of terminal illness and that the patient and physician or family and physician are in

agreement that the medical care should be palliative? (4) What should be the realm of independent nursing judgment in the care of terminally ill patients? Is the command in agreement with the privileges, comfort items and quality of life items that the nurses rated as significant when providing care to terminally ill patients? (5) What additional resources are available or can be made available to assist the nurses in providing quality nursing care to terminally ill patients? (6) Although the questions eight and ten did not rank as significant, because of their large S.D.s there appears to be a need for the command to evaluate these issues and formally or informally provide the nurses with some additional insight to help them when confronted with these problems. What considerations should the nurse evaluate when deciding whether or not to share the patient's chart with him or his family; and is approaching a family about "no code" strictly a physician's responsibility?

Recommendations

Based on the results of the research, it is recommended that specific hospital command guidance be developed to address those questions listed in the conclusions. Development of a written hospital policy would provide the professional staff with the clearest and most legally acceptable interpretation of what the command guidance is regarding the management of terminally ill patients who have reached the pre-death stage. A professional staff conference on at least an annual basis, should be held to

discuss current legal and professional development that impact on this area of health care. A staff conference format would facilitate the interpretation of written guidance and encourage the voicing of new concerns. It is doubtful that this guidance would lay to rest all concerns regarding care of the terminally ill patient. Results of the survey do strongly indicate the need for a "code" or "no code" decision point with adequate communication among all those involved. Since HSC guidance and current hospital guidance state that resuscitation consideration will be made on an individual basis, hospital guidance should indicate what is expected as documentation of that resuscitation decision. The hospital command should continue to communicate the need for a "code" or "no code" policy with HSC.

In addition, it is recommended that a multidisciplinary approach be encouraged when assessing a terminal patient's needs. This type of approach should best use the available hospital resources without placing excess burden on the nursing staff to provide for all the physical and psychosocial needs of the patient. Group discussion among the various care providers should be focused on quality care without duplication of efforts.

The last recommendation is one concerning education. The obvious confusion and uncertainty that was reflected in the responses to this survey and is also seen in the literature indicates an engoing need for education concerning death and dying at this hospital and throughout the Army Medical

Department. It is recommended that appropriate expert counseling be solicited from within or outside MACH to address the needs of the nurses when dealing with the physiological and emotional espects of death and dying, thereby assisting the individual nurse to deal more constructively with both the issue of "no code" and the natural death of the patient.

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APPENDIX A

DEPARTMENT OF THE ARMY



MEADQUARTERS UNITED STATES ARMY MEDICAL DEPARTMENT ACTIVITY FORT JACKSON, SOUTH CAROLINA 29267

REPLY TO ATTENTION OF

12 January 1984

Dear Nurse:

The attached questionnaire concerned with situations where there is an implicit indication in a terminally ill patients medical record requesting non-resuscitative procedures either by patient or family and/or primary physician, is part of a hospital study being conducted as an Army-Baylor Health Care Administration Graduate Research Project. The project is concerned specifically with determining the guidance required by nurses from the local command when faced with the above situation. It is essential that one hundred percent of nurses who provide primary care to terminally ill patients participate in this survey of the research is to be valid.

I am particularly desirous of obtaining your responses because your experience with terminally ill patients in the military system will contribute significantly toward the knowledge needed to deal with some of the problems we face in this important area of health care. The enclosed questionnaire has been validated by expert review. Time required to complete the questionnaire is about twenty minutes.

I would appreciate your completing the questionnaire within three days and returning it through the Message Center to MAJ Ross, Nursing Methods Analyst, Comptroller Division. Any comments you may have about the topic are welcome. Contact me at EXT 2125/2379 for questions, clarification or discussion concerning the questionnaire. You need not identify yourself on

ATZJ-AC

SUBJECT: Dear Nurse

12 January 1984

the questionnaire unless you would like a summary of the questionnaire results.

Thank you for your cooperation.

Sincerely yours,

SANDRA V. ROSS MAJ, ANC Nursing Methods Analyst B MIC, Baca

Registered Nurse Questionnaire: Care of Terminally Ill Patients

DIRECTIONS:

- 1. The questionnaire contains 25 questions, three of which have several parts requiring individual answers. Those three questions also request additional written comments if you wish to make such.
- 2. Each question is answered by circling one answer on a seven part attitude scale that ranges from strongly disagrees to strongly agrees. Please circle the number that corresponds most closely with your personal feeling about the question being asked.
- 3. Please keep in mind that the entire ouestionnaire deals with care of terminally ill patients during the pre-death stage and for whom medical care is no longer curative in nature.
- 4. Please answer all ouestions independently and as honestly as possible. All questionnaires are anonymous. Demographic data is for statistical purposes only.

Thank you.

Demographic Data

- 1. Your age group:
 - a. 26 or younger
 - b. 27 to 34
 - c. 35 to 42
 - d. 43 to 50
 - e. Over 50
- Your area of practice is:
 - a. Medical
 - b. Surgical
 - c. Pediatrics
- 3. You are: a. Male b. Female
- 4. You are: a. Military b. Civilian
- 5. How many end stage terminally ill patients have you cared for approximately:
 - a. None b. 1 to 5 c 6 or more
- 6. Your level of nursing education is:
 - a. Associate Degree b. Diploma c. BSN d. Other

	56 SURVEY QUESTIONNAIRE	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISACREE	NEUTRAL,	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY ACREE
on how '	ses face a great amount of uncertainty to work in particular settings with l patients.	1	2	3	4	5	6	7
	nurses lack education in the ent of terminally ill patients.	1	2	3	4	5	6	7
termina	goal of nursing care for the lly ill is to improve the quality of r the patient and their family.	1	2	3	4	5	6	7
the fol	rovec Quality of Life might include lowing items. Indicate your agreement greement with each item in this y.							
ĉ.	To decrease pain and other symptons associated with disease.	1	2	3	4	5	6	7
ь.	To decrease depression, anxiety, and anger.	1	2	3	4	5	6	7
с.	To increase satisfaction of care.	1	2	3	4	5	5	7
đ.	To improve the physical environment.	1	2	3	4	5	6	7
₽.	To decrease diagnostic interventions (Lab and Radiographic test).	1	2	3	4	5	6	7
f.	To increase opportunity to affect the course of treatment.	1	2	3	4	5	6	7
9.	To increase choice of location of care and ceath.	1	2	3	4	5	6	7
h.	To increase patients functional activity.	1	2	3	4	5	6	7
i.	To decrease the families ill-effects during bereavement. (Help the family understand and cope with the events surrounding terminal illness).	1	2	3	4	5	6	7
j.	To promote open communication between significant other and patient about death.	1	2	3	4	5	6	7

59	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	NEUTRAL.	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
 k. To assist patient in making final preparation as desired. 	1	2	3	4	5	6	7
* List other Quality of Life items you feel should be included:							
5. Hospital and ward rules should be relaxed to accommodate the physical, psychological and social needs of the terminal patients as long as care to other patients is not impaired.	1	2	3	4	5	E	7
E. The charge nurse should have the right to relax ward rules as she/he deems appropriate for the situation.	1	2	3	4	5	6	7
7. The following is a list of items that might be considered as privileges for the terminally ill. Please indicate your degree of agreement or disagreement with each item.							
a. Adult visitors at any time.	1	2	3	4	5	Е	7
b. Visits by children.	1	2	3	4	5	6	7
c. Visits by small household pets.	1	2	3	4	5	ε	7
d. Smoking.	1	2	3	4	5	6	7
e. Alcoholic drinks in moderation.	1	2	3	4	5	6	7
f. Television, radio or tape player left on when desired.	1	2	3	4	5	6	7
g. Special personal items brought to hospital (ex: pillow, tape recorder, chair).	1	2	3	4	5	6	7
h. Privacy as desired.	1	2	3	4	5	6	7

	60	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	NEUTRAL	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
i.	Wearing own clothes.	1	2	3	4	5	6	7
j.	Allowing patient to go outside the hospital as much as possible with family or friends.	1	2	3	4	5	6	7
k.	Direct admission to the ward when the patient or family feels the need for hospitalization (by pass the Emergency Room whenever fesible).	1	2	3	4	5	6	7
1.	Any type of food from outside the hospital.	1	2	3	4	5	6	7
m.	Allow patient to participate in decisions about his care.	1	2	3	4	5	8	7
	any other privileges you feel should d to this list.							
to keep the pat express 9. Th	e nurse should share the patient's ith family or patient as appropriate the family and/or patient informed of ient's status and care plan (as they a need to know). e nurse should keep the physician d of the patients or families needs	1	2	3	4	5	6	7
	nursing care planned to meet those	1	2	3	4	5	6	7
	e nurse should approach the family esuscitative measures if the patients							

1 2 3 4 5 6 7

5 6 7

2 3 4

10. The nurse should approach the family about resuscitative measures if the patients condition is worsening or death appears imminent and "no code" had not been made explicit at all.

11. The nurse should explain alternatives of care and define terms or explain equipment whenever she/he see the need.

	61		ഥ					
		STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	NEUTRAL	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
12. One nurse resource person should be assigned to each patient and their family for them to contact at anytime they feel the		STR	MOD	SLIG	NF.U	SLI	MOD	STR
need.		1	2	3	4	5	ε	7
nursing ,	sing care involves independent judgment based on the patients and expected outcome.	1	2	3	4	5	6	7
initiate	nurse should be authorized to or employ any comfort measures etermines are needed.	1	2	3	4	5	6	7
include to by the no	term "comfort measures" might the following items to be initiated urse. Please indicate your agreement reement with each item.							
â.	Positioning.	1	2	3	4	5	ε	7
ь.	Skin care.	1	2	3	4	5	6	7
C •	Oral hygiene and lip care.	1	2	3	4	5	6	7
ø.	Suctioning.	1	2	3	4	5	6	7
е.	Oral air way.	1	2	3	4	5	6	7
f.	Skin care devices or equipment (ex: Air mattress, sheepskin).	1	2	3	4	5	6	7
g •	Oral fluids or nutrition as tolerated.	1	2	3	4	5	Б	7
h.	Oxygen on (if patient desires).	1	2	3	4	5	6	7
i.	Oxygen devices taken off (ex: Nasal canula or mask if uncomfortable).	1	2	3	4	5	٤	7
j•	Nasal gastric tube inserted.	1	2	3	4	5	6	7
k.	Nasal gastric tube removed (if patient desires).	1	2	3	4	5	6	7

	62	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	NEUTRAL	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
1.	Room environment adjusted (ex:	ST	<u>C</u>	\mathbf{SL}	Z F	SL	Σ	ST
	temperature, lighting, noise level).	1	2	3	4	5	6	7
n. •	Eye drops.	1	2	3	4	5	6	7
n.	Bathing, hair shampooing, shaving.	1	2	3	4	5	6	7
c.	Flexible schedule to allow patient to sleep.	1	2	3	4	5	6	7
D.	Odor control in roor.	1	2	3	4	5	6	7
g.	Therapeutic touch.	1	2	3	4	5	6	7
r.	Nail care, make-up as needed or desired.	1	2	3	4	5	Б	7
٤.	Pain medication as ordered if needed.	1	2	3	4	5	6	7

* List any other comfort measures you feel should be included:

16. Routine multi-disciplinary (Dietician, Social Service, Chaplain, Physical Therapist, etc) hospital rounds should be conducted to assist in developing the patients care plan.

17. Supportive care for the patient includes supportive care for the family regardless of their military eligibility.

1 2 3 4 5 6 7

1 2 3 4 5 E 7

63		REE	نعة				
	DISAGRE	LY DISAG	DISAGREE		AGREE	LY AGREE	ACREE
18. If there is an implicit indication (no written order) in the medical record that the patient or family and/or primary physician request non-resuscitative procedures, then in the event of respiratory, or cardiac arrest, CPR should not normally be initiated.	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY	NEUTRAL	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY
	1	2	3	4	5	6	7
19. You are adequately prepared to provide care to terminally ill patients and their significant others.	1	2	3	4	5	6	7
20. You clearly understand what is expected of you in the care of terminally ill patients.	1	2	3	4	Ľ,	6	7
21. You would like explicit guidelines regarding nursing care of terminally ill patients and their families when non-resuscitative measures are implied in the medical record.	1	2	3	4	5	£	7
22. The focus and nursing care approach for a terminally ill patient changes from curative to supportive and comfort once a non-resuscitative plan is implied.	1	2	3	4	5	6	7
23. It is essential to verify the code/no code status of a patient if appropriate nursing care is to be given.	1	2	3	4	5	6	7
24. Open, honest communication with a patient and his family greatly improves their perception of the care being given.	1	2	3	4	5	6	7
25. Good communication with the patient and family is the key to decreasing risk of a malpractice suit.	1	2	3	4	5	6	7

APPENDIX C

DISPOSITION FORM

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REFERENCE OR OFFICE SYMBOL SUBJECT

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16 Nov 82 MAJ Dicks/jbp/2361

- 1. Hospital Policy, Serial Number 021, SAB, is rescinded, effective immediately.
- 2. The current guidance from Health Services Command concerning the care of terminally ill patients in the event of cardiac or respiratory arrest is that "the only possible rule for dealing with such directives to physicians is to prohibit their use in Army medical treatment facilities...Army medical treatment facilities or their personnel should be prohibited from honoring directives to physicians requesting withholding or withdrawal of life-sustaining procedures for the terminally ill." DAJA-AL 1978/2402, 8 May 1978.
- 3. The Office of The Surgeon General's guidance is that "Neither the 'Directive to Physicians' (referring to Texas) nor any similar directives regarding the withholding or withdrawal of life-sustaining procedures will be accepted or honored by Army medical treatment facility personnel."
- 4. Further..."Determinations concerning the application or withdrawal of life-sustaining procedures will continue to be made in accordance with accepted medical practice with due regard to the rights of the patient concerned and all medical, regulatory, and legal considerations involved. Legal questions will be referred to the appropriate judge advocate or legal advis a on a case by case basis."
- 5. There will be no policy regarding he above at Monoriof Army Hospital. Each patient will be handled on an individual basis as per above guidelines.

FOR THE COMMANDER:

DISTRIBUTION: A

Sylvia Beck Stria BECK ALT, MSC

Adjutant